

Measuring the Burden of Disease

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Presentation Outline:

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- **Summary measure of Population health:**
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 - Criticism of G B D Methodology
- **Critical review of DALY by Experts.**

Introduction:

Precise information about diseases and injuries, their incidences, their consequence, their causation and their trend is necessary to inform policy-making.

An important part of the W H O's work has been to develop and publish summary measures of the burden of disease for different nations. The WHO aims to measure both the overall burden that disease and ill-health impose on a nation and the burdens imposed by individual diseases. Its measures are intended to provide general indicators of how a nation's health is progressing, and also to guide the setting of priorities in health care.

Summary measures of population health are measures that combine information on mortality and non-fatal health outcomes to represent the health of a particular population as a single number.

Historical Aspects:

Evolution of Summary Measure of Population Health:

- In 1940s Dempsey's concept of using "Years of Life Lost" was used as a metric for assessing the health burden associated with deaths occurring prior to an 'ideal' life span of 65 years.

- Following the pioneering work of Dempsey (1947), various measures of years of life lost due to premature mortality have been proposed. All are examples of “mortality gaps”, or the area labeled C in Survival Curve.
- Sullivan Index Developed in 1971 emphasized on (a) the expectation of life free of disability and (b) the expectation of disability. Either of these measures can be calculated using various definitions of disability (1).
- Wilkin and Adams (1983) published a paper on Health expectancy on Canada and proposed a new measure that is Quality Adjusted Life Expectancy (Q A L E).
- 1992, Global Burden of Disease commissioned by World Bank and WHO. Developed Summary Measure Disability Adjusted Life Years (DALYs).
- 1993, World Development Report: Investing on Health used the term DALY for the first time to describe summary measure of population health (2).
- 1998, Hyder AA, et al. Published a new indicator called Healthy Life Years (HeaLY). HeaLY incorporates Mortality and Morbidity in to a Single number.
- HALE (Health adjusted Life Expectancy) came in to picture during early 2000 which mainly emphasizes on Health Expectancy as compared to Health Gaps approach of DALYs(3).
- Disability-free life expectancy (DFLE) has been recommended as a summary measure of population health and reported for OECD countries for some years in its health database.
- Efforts to develop summary measures of population health have a long history and in past two decade, there has been a markedly increased interest in the development, calculation and use of summary measures.

WHY S M P H is Important:

Why would we want a single number of this form?

The simplest and most widely used method for producing population health statistics is to aggregate data on individuals in order to generate statistics like the proportion of the population (or of a particular age – sex group) suffering from a particular health problem or in a particular health state. This approach rapidly becomes difficult when a number of problems are being monitored and we want to make comparisons over time, across population groups, or before and after some health intervention. We are then faced with an explosion in the numbers of statistics that must be compared. Summary measures of population health allow us to summarize all these numbers in a comprehensive and consistent manner(4).

The potential applications of S M P H are (5):

- Comparison of health conditions or overall health status between two populations or the same population over time.
- Quantification of health inequalities.
- Inclusion of non-fatal health outcomes to ensure this condition receives appropriate policy attention.
- Measurement of the magnitude of different health problems using a common metrics.

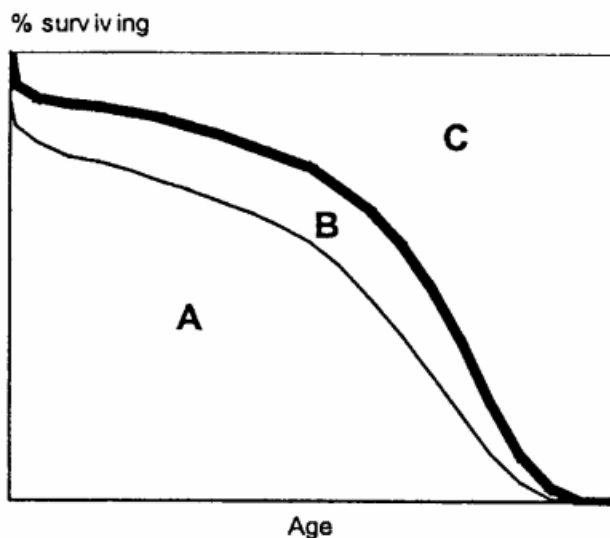
- Analysis of the benefits of health interventions for use in cost-effectiveness studies; and
- Provision of information to assist in setting priorities for health planning, public health programs, research and development, and professional training.

Summary measures of population health can be classified into two classes:

- **Health expectancies:** (i.e. Disability free life expectancy, disability adjusted life expectancy) and
- **Health gaps:** (i.e. Disability-adjusted life years, healthy life years).

These two classes of measures are complementary. Both classes of summary measure use time (lived in health states or lost through premature death) as an appropriate common metric for measuring the impact of mortality and non-fatal health outcomes.

The Survivorship Curve:



The Bold Line: The survivorship curve from a hypothetical life table of population.

The Thin Curve: Hypothetical curve of survivors to each age x in optimal health.

Area A: Represents time lived in optimal health.

Area B: Time lived in suboptimal health.

Area C: Represents time lost due to mortality.

Total Life Expectancy at Birth:

$$L. E. = A + B$$

Health expectancies are population indicators that estimate the average time (in years) that a person could expect to live in a defined state of health.

Examples:

Disability-free life expectancy (DFLE),

Active life expectancy and

Disability-adjusted life expectancy (DALE)

$$HE = A + f(B)$$

Where 'f' is some function that assigns weights to years lived in suboptimal health (optimal health has a weight of 1).

Measures of potential years of life lost due to premature mortality have been used for many years to measure the mortality burden of various causes of death. These all measure the gap in years between age at death and some arbitrary standard.

Health gaps measure the difference between actual population health and some specified norm or goal.

$$\text{Health gap} = C + g(B)$$

Where 'g' is some function that assigns weights to health states lived during time B, but where a weight of 1 equates to time lived in a health state equivalent to death.

Health gaps extend the notion of mortality gaps to include time lived in states of suboptimal health i.e. part of area B in Survival Curve.

The principle characteristic defining a health gap measure is the population norm (age) chosen to define the period before which death or disability is considered premature.

Relating Summary Measure of Health to Causes:

One of the fundamental goals in constructing summary measures is to identify the relative magnitude of different health problems, including diseases, injuries and risk factors. There are two dominant traditions in widespread use for causal attribution: **Categorical attribution** and **Counterfactual analysis**.

1. **Categorical attribution:** In this an event such as death is attributed to a single cause according to a defined set of rules. Such rules are insensitive in dealing with multicausality and co-morbidity.
2. **Counterfactual analysis:** The contribution of a disease, injury or risk factor is estimated by comparing the current and future levels of a summary measure with the levels that would be expected under some alternative hypothetical scenario. For example, we could ask what the burden of disease would be if no one in population ever smoked. By comparing this estimate with the actual current burden, we can estimate the attributable burden of tobacco smoking.

Health gap measures use categorical attribution to attribute the fatal and non-fatal burden of diseases and injuries to an exhaustive and mutually exclusive set of disease and injury categories. Contribution of disease causes to overall health expectancy measure, as well as for dealing with risk factors.

Sullivan's Index:

Proposed in 1971 by Daniel F Sullivan the Sullivan index combines death rates with illness rates. Expectation of Life Free of Disability = Life Expectancy – Duration of Disability & Inability to perform major activities.

It doesn't take into account the severity of disability.

The two related indices were also described based upon a life table model.

They were

- (a) The expectation of life free of disability and
- (b) The expectation of disability.

The expectations of life and of disability are hypothetical values derived from a period life table. They are the values which would occur if a birth cohort of fixed size experienced age for age throughout life, the recent age-specific mortality and disability rates used in these life table calculations.

Quality Adjusted Life Expectancy (QALE)

Health implies not only survival, but also a certain quality of life. Although average life expectancy is increasing, so is the apparent prevalence of sickness and disability in the population. A comprehensive index of population health status should take into consideration not only the overall length of life, but also the healthfulness of life, states of health and the sum of expected years of institutionalization plus expected years of disability not involving institutionalization.

Quality-adjusted life expectancy can be calculated by applying weights to the expected years in each state of health, and then summing the products.

DALE: Disability Adjusted Life Expectancy

The primary summary measure of population health used was Disability-Adjusted Life Expectancy, or DALE, which measures the equivalent number of years of life expected to be lived in full health.

World Health Report 2000, the World Health Organization (WHO) reported for the first time on the average levels of population health for its 191 member countries using a summary measure that combines information on mortality and disability. Later the name changes to HALE.

HALE – Health adjusted life years.

Average number of years that a person can expect to live in full health by taking in to account years lived in less than full health to due to disease and / or injury.

Substantial resources are devoted to reducing the incidence, duration and severity of major diseases that cause morbidity but not mortality and to reducing their impact on people's lives. It is important to capture both fatal and non-fatal health outcomes in a summary measure of average levels of population health. Healthy life expectancy (HALE) at birth adds happy expectation of life for different health states, adjusted for severity distribution making it sensitive to changes over time or differences between countries in the severity distribution of health states.

Disability-free life Expectancy:

The difference between life expectancy in all states of health and the sum of expected years of institutionalization plus expected years of disability not involving institutionalization.

Global Burden of Disease study(6):

This measure was used in The Global Burden of Disease and Injury (GBD), a joint study between the World Bank, the World Health Organization (WHO) and Harvard School of Public Health, which began in 1988 with the objective to quantify the burden of disease and injury of human populations and define the world's main health challenges.

Major Objectives of GBD study (7):

- a) To facilitate the inclusion of non-fatal health outcomes in the debate on international health policy which were all too often focused on mortality in children under 5 year of age?
- b) To decouple epidemiological assessment from advocacy so that estimates of mortality and disability from a condition are developed as objectively as possible and,
- c) To quantify the burden of disease using a measure that could also be used for cost-effectiveness analysis.

Disability Adjusted Life Years (8):

The DALY was designed to meet these objectives. Using DALYs, the GBD was measured for 1990 and projections were developed to 2020 for the first time.

The DALY extends the concept of potential years of life lost due to premature death (PYLL) to include equivalent years of 'healthy' life lost by virtue of being in states other than good health. DALYs for a disease or health condition are calculated as the sum of the years of life lost due to premature mortality (YLL) in the population and the equivalent 'healthy' years lost due to disability (YLD) for incident cases of the health condition (5):

$$\text{DALY} = \text{YLL} + \text{YLD}$$

Social Values Incorporated in Calculating DALYs (9):

The five key social preferences or values that are incorporated into the indicator of burden of disease "DALY" are the following:

- ***Duration of time lost due to a death at each age:***

This is used to measure years of life lost due to premature mortality (or the number of years of life gained by averting death).

This measurement requires defining the potential limit of life; in the case of DALYs, standard years of life lost are used. The standard has been chosen to match the highest national life expectancy observed, which that of Japanese women is (82 years). For a specific standard, the expectations are based on model life-table, which has a life expectancy at birth for females of 82.5. The potential life expectancy at birth for males has been set at 80.1.

- ***Disability weights***

Degrees of incapacity or suffering associated with different non-fatal conditions, which are necessary to make comparisons across diseases, as well as for comparing time lived with a disability with time lost due to premature mortality. Six disability classes measuring the extent of loss of physical functioning associated with a certain condition were defined. Subsequently, a group of independent experts established a weight, ranging from 0 (perfect health) to 1 (death), for each of the six disability classes.

- **Age-weights,**

Which indicate the relative importance of healthy life at different ages? The age weights used in the World Bank report rise from birth until age 25 and decline slowly thereafter. According to the World Health Organization (1994), the formula to calculate those weights is:

$$\text{Age - Weighting Function} = Cx e^{Bx}$$

Where:

C = Constant equal to 0.16243.

B Constant equal to 0.04.

x Age.

e Constant equal to 2.71

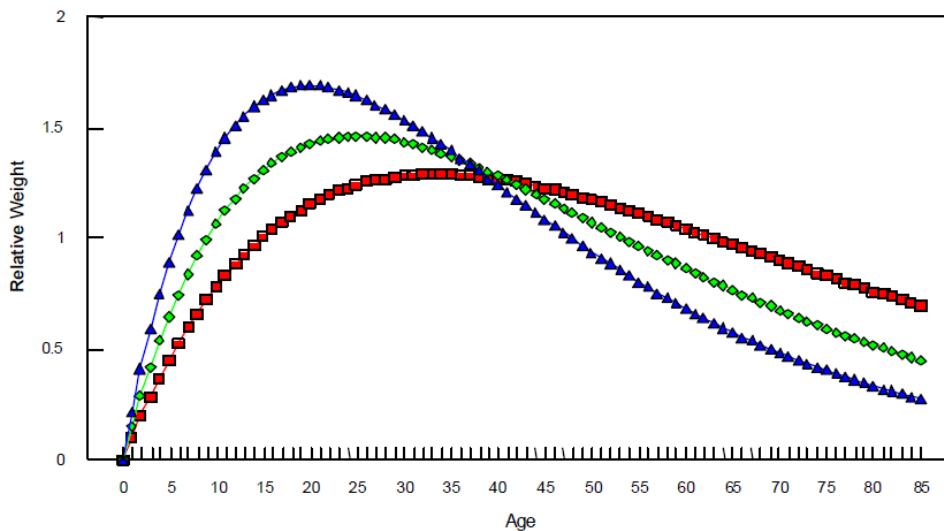


Figure: Value of a Year of Life Lived at Different Ages for Various Values of Beta

- **Time preference:**

Which is the value of health gains today compared to the value attached to health gains in the future (in standard economic theory, the latter is assumed to be lower than the former). It is standard practice in economic appraisal of projects to use the discount rate to discount benefits in the future. The process of discounting future benefits converts them into net present-value terms; these benefits can then be compared with project costs (also discounted if they are spread over more than one year) to determine cost-effectiveness.

The discount rate used in the DALY formula is 3 percent. The formula to discount for time preference is:

$$\text{Discounting Function} = e^{-r(x-a)}$$

Where:

r = Discount rate, fixed at 0.03

x = Age.

e = Constant equal to 2.71

a = Onset year.

Discounting of future benefits is standard practice in economic analysis and there are some specific arguments for applying discounting to the DALY in measuring population health.

- To be consistent with measurement of health outcomes in cost-effectiveness analyses;
- To prevent giving excessive weight to deaths at younger ages (without age weighting and discounting, a male death at age zero results in 44% more YLL than a death at age 25 and 97% more than a death at age 40; with discounting at 3% an infant death results in only 12% and 29% more YLL than a death at age 25 and age 40, respectively); and
- The disease eradication/research paradox: assuming that investment in research or disease eradication has a non-zero chance of succeeding, then without discounting, all current expenditure should be shifted to such investment because the future stream of benefits is infinite. This is a particular case of the excessive sacrifice argument.

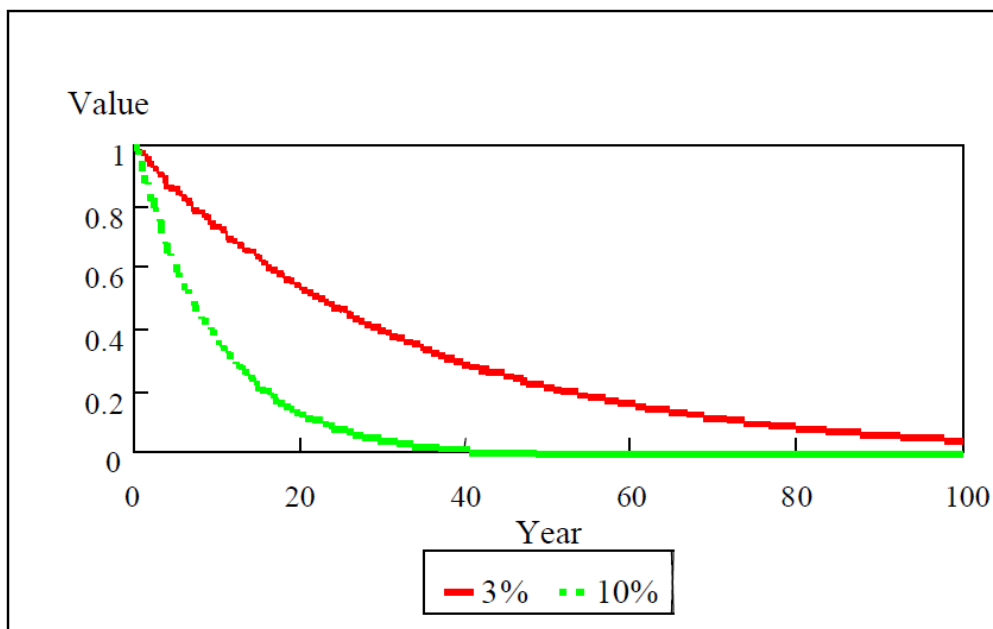


Figure: *Effect of Discounting in a Year of Life lost at various time in the future*

ESTIMATING YEARS OF LIFE LOST DUE TO PREMATURE MORTALITY: (YLL)

Standard Expected Years of Life Lost (SEYLL) method has been adopted. This uses the expectation of life at each age x based in some ideal standard to estimate the loss of years of life associated with a death.

SEYLL has several advantages:

- a) Deaths at all ages contribute to the calculation of the burden of disease; and
- b) Deaths at the same age contribute equally to the burden of disease.

$$YLL = N \times L$$

- Where, N = number of deaths

L = standard life expectancy at age of death in years

EPIDEMIOLOGICAL ESTIMATES FOR DISEASES: (YLD)

Years of life Lost due to Disability (YLD) are the disability component of DALYs. Estimating YLD is the most difficult component of an NBD study. It will frequently require an in depth understanding of the epidemiology of particular diseases in order to identify alternative estimation methods and will involve the use of judgment and creativity.

Data required: disability incidence, disability duration, age of onset, and distribution by severity class, all of which must be disaggregated by age and sex. These in turn require estimates of incidence, remission, case-fatality rates or relative risks, by age and sex. With zero discounting and uniform age weights, the basic formula for calculating YLD is:

$$YLD = I \times D W \times L$$

Where I is the number of incident cases in the reference period, D W is the disability weight (in the range 0-1) and L is the average duration of disability (measured in years).

The Steps in Calculating the YLD:

- Research current knowledge of the disease
- Construct diagram of the natural history of the disease
- Identify the epidemiological indicators to be estimated
- Review the published and non-published data available
- Check data consistency and quality
- Apply data to calculate YLD.

Health is simply added across individuals:

That is, two people each losing 10 years of disability-free life are treated as the same loss as one person losing 20 years. One could also weight duration non-linearly, so as to give priority to fewer people suffering for long interval so more people suffering for shorter interval.

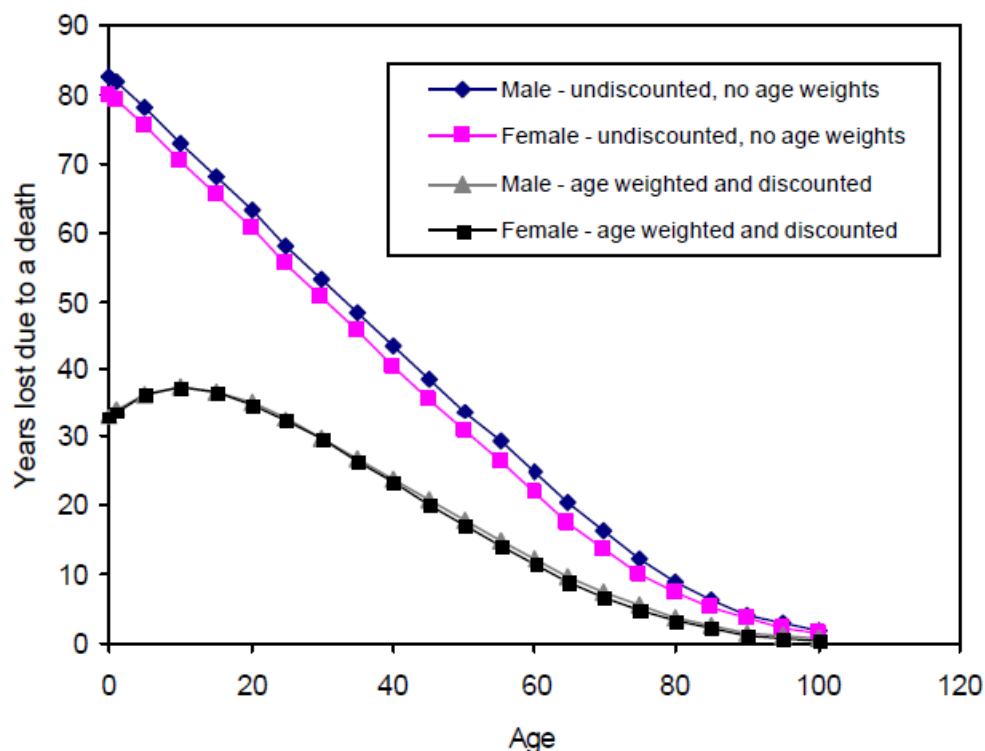
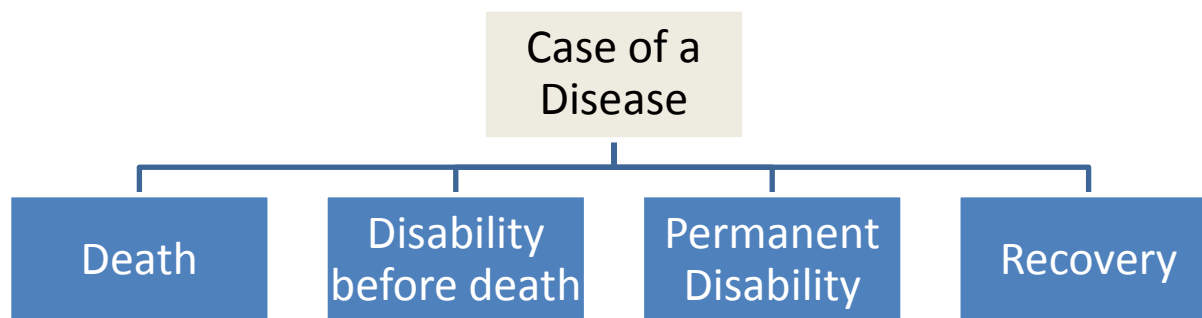


Figure: The Value of Years of Life Lost Due to a Death at Varying Ages by Sex, with and without Discounting and Age Weighting.

Procedure to Calculate DALY:



The example corresponds to a female child who contracts poliomyelitis at age five. As a result she can die; she can live for a period of 5 years and then die; she can be permanently disabled; or she can recover after a period of disability.

Assumption:

Life Horizon: 82.5 Years

Disability weight for this case: 0.5

Scenario 1: Baby dies at 5 years of age: Immediate death.

The number of DALYs lost to premature mortality is equal to 35.85.

Scenario 2: DALYs Lost Due to Death Following Disability.

Baby becomes disabled at age 5, lives with disability for 5 years and then finally dies at an age of 10 years.

In this case we have to calculate the number of DALYs lost due to disability and the number of DALYs lost due to premature mortality. The number DALYs lost due to disability are 2.0.

The number of DALYs lost due to premature death are 36.85 years. Those 36.85 years are the DALYs calculated at the age of 10; to add them up with the DALYs lost due to disability calculated at age of onset (5 years), we have to convert the 36.85 DALYs calculated at age 10 to their value at the age of onset of the disease, that is at age 5. That is, at the time of the onset of the disease (5), the number of DALYs lost due to premature mortality at age 10 equals the number of DALYs lost at age 10 (36.85) times 0.86, which is 31.7 years.

Total DALYs Lost = 2 + 31.7 = 33.7

Scenario 3: DALY lost due to permanent disability:

Baby become permanently disabled at age 5 but went to live till expected life span.

The total number of DALYs lost due to permanent disability equals to 17.92.

Scenario 4: DALYs Lost Due to Disability Followed by Complete Recovery.

Suppose the baby had disability at age 5 and recovered by the time she was 10 years of age.

The number of DALYs lost to disability equal to 2.0 years.

This example was an individual example and since the DALY is summary measure of population health, we are concerned with calculation of DALY in a community.

Suppose:

20 cases of Poliomyelitis at age 5 years, 4 dies immediately, 4 dies at age 10 after 5 years of disability, 4 of them are permanently disabled, and 5 recovered.

$Total\ DALYs\ lost = 5 \times (35.85) + 5 \times (33.7) + 5 \times 17.92 + 5 \times 2 = 447.4$

Data Needed to Estimate the Burden of Disease:

Age and Sex Specific causes of Death needed to calculate the years of life lost to premature death.

To measure the time lived with a disability in a manner that can be meaningfully compared with the time lost due to premature mortality:

- (i) Age and gender specific information on the incidence of disease.
- (ii) The proportion of disease incidence leading to a disabling outcome.
- (iii) The average age of disability onset the duration of disability, and
- (iv) The distribution of disability across the six classes of disability severity.

But because of the scarce and unreliable data on these indicators, there are chances of error. These errors can happen at two places:

1. Some disabilities might have been omitted, which would give a downward bias to estimates of the years lived with disability, and
2. The computations do not take into account co-morbidity (an individual experiencing multiple illnesses) and biases the results upwards.

Cost Effectiveness Analysis:

Because cost-effectiveness analysis is based on gains associated with health interventions, the next step is to identify appropriate health services and to estimate their effectiveness in reducing disease burden. Cost-effectiveness shifts the focus decisively from individuals, or groups, to interventions.

To select a set of interventions to be evaluated using cost-effectiveness analysis, the following factors need to be considered:

- (i) Standard of best practice;
- (ii) Health care infrastructure and organization;
- (iii) Focus on prevention or treatment;
- (iv) Potential for clustering interventions, some health interventions give rise to multiple health benefits;
- (v) Feasibility and acceptability of interventions.
- (vi) Potential cost of interventions and alternative strategies; and
- (vii) The effectiveness of the strategy in reducing the disease burden.

Data Needed to Estimate Cost-Effectiveness:

The cost of an intervention is a function of:

- (i) The quantity, type, and quality of inputs used; and
- (ii) The price of those inputs.

Because personnel and equipment are frequently shared among health services within the same facility, it is necessary to derive rules-of-thumb for allocating a portion of input cost to specific health interventions. Unfortunately, there is no universally used framework to evaluate the costs of health services.

As mentioned earlier, in order to calculate the number of DALYs gained from health interventions, the impact of each intervention in reducing disease burden must be estimated. The effectiveness of a health intervention depends on: (i) efficacy of the technology used; (ii) diagnostic accuracy;

- (iii) Compliance of health care providers; and, (iv) compliance of patients. Since few empirical studies have evaluated the effectiveness of interventions in various settings, this aspect of the cost-effectiveness exercise is very subjective; most effectiveness estimates are based on opinions and judgments of health professionals.

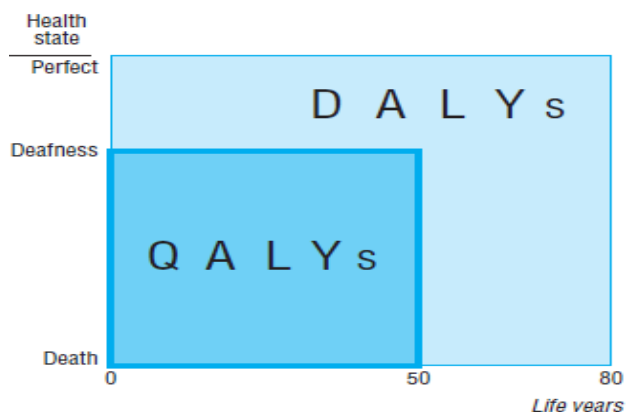
The problems of GBD methodology (10):

- The need to expand and improve the list of diseases included in the burden of disease exercises.
- The need to improve and validate the method to measure the time lived with disabilities of different severity.
- The lack of methods to adjust for both dependent and independent co-morbidity.
- The inability to quantify the contribution of risk factors in total burden of disease.
- The lack of unit cost production functions to be used widely by researchers doing cost-effectiveness studies.
- The need for more accurate monitoring systems to be able to generate real estimates of mortality and disability by cause.
- The need of projection methods that incorporate known levels and trends The need of projection methods that incorporate known levels and trends of major risk factors such as smoking and trends in other diseases.

The **criticisms** that have been made to the methodology include the following (11):

- Requires a lot of data that is not readily available.
- It is an expensive exercise.
- Decisions are made by a group of experts with little involvement of health care providers, interest groups or beneficiaries.
- The methodology is very complicated and does not add much information to what public health specialists already know.
- It discriminates against the elderly(12).
- The manner in which the information is manipulated is subjective.
- It is difficult to create demand for services that are cost-effective.
- The value choices that underlie the definition of the DALY are not universally accepted(13).
- The method assumes that disabled people are less entitled to scarce health resources for interventions that would extend their lives.

DALY and QALY (14):



DALYs and QALYs are complementary concepts. QALYs are years of healthy life lived; DALYs are years of healthy life lost. Both approaches multiply the number of years (x axis) by the quality of those years (y axis). QALYs use “utility” weights of health states; DALYs use “disability weights” to reflect the burden of the same states. For example, if the utility of deafness is 0.67, the disability weight of deafness is $1-0.67=0.33$. Disregarding age weighting and discounting, and assuming life expectancy of 80 years, a deaf man living 50 years represents $0.67 \times 50 = 33.4$ QALYs gained and $0.33 \times 50 + 30 \times 1 = 46.6$ DALYs lost.

Health Life Expectancy (HeaLY) (15):

The Healy is a composite measure that combines the amount of healthy life lost due to morbidity with that attributable to premature mortality. It can be applied to individuals or to population groups to determine the impact of a particular disease, to work out the effects of an intervention, or to compare areas, populations, or socioeconomic groups.

Critical review of DALY by Experts (11). (S. Anand & K. Hanson, 1996)

Raised issue of serious flaws in technical basis of DALY. Particularly in Age and Disability Weighting.

- Burden of Disease:
 - Disability weighting: Disability Class is distinguished.
 - 0 for optimal health and 1 for death. Death is merely complete disability. Information about death rate and morbidity should be separate.
 - Highest Life Expectancy is expected. Health intervention alone is not capable of doing so.
- Standard expectation of Life and Gender Gap.
 - 82.5 and 80 for female and male: Highest life expectancy.
 - Biological Gap is of 2.5 years, actually the gap is 6 years.
 - WHO: Burden of Disease in female is 10% less than Males.
 - If true biological gap is more, than underestimate in disease burden of female
- Age Weighting:
 - Unequal Weight at different age don't constitute a differential intrinsic valuation of year lived at different age.
- Disability weight:
 - Weight for 6 classes chosen by the experts. DALY doesn't distinguish the quality of ill health and burden associated with it.
- Time Preference and discounting for future life:
 - No Justification for an estimation of time lost due to illness or death which depends on when the illness or death occurs.

References:

1. Sullivan DF. A single index of mortality and morbidity. HSMHA Health Rep. 1971 Apr;86(4):347-54.
2. World Bank: World Development Report; Investing in Health. New York 1993.
3. R Bonita RB, T Kjellstrom., editor. Basic Epidemiology. second ed. Geneva: WHO; 2004.
4. R Detel JM, R Beaglehole, Tanaka Heizo, editor. Oxford Textbook of Public Health. Fourth ed. New York: Oxford University Press; 2004.
5. Homedes N. Disability Adjusted Life Years; Definition, Calculation and Potential use. Human Capital Development; Working Papers: World Bank; 1996. p. 2 -12.
6. Lopez AD, Mathers CD, Ezzati M, Jamison DT, Murray CJL. Measuring the Global Burden of Disease and Risk Factors, 1990-2001. 2006.
7. Lopez AD, Murray CC. The global burden of disease, 1990-2020. Nat Med. 1998 Nov;4(11):1241-3.
8. Murray CJ. Quantifying the burden of disease: the technical basis for disability-adjusted life years. Bull World Health Organ. 1994;72(3):429-45.
9. Murray CJ, Lopez AD. Quantifying disability: data, methods and results. Bull World Health Organ. 1994;72(3):481-94.
10. Murray CJ, Lopez AD, Jamison DT. The global burden of disease in 1990: summary results, sensitivity analysis and future directions. Bull World Health Organ. 1994;72(3):495-509.
11. Anand S, Hanson K. Disability-adjusted life years: a critical review. J Health Econ. 1997 Dec;16(6):685-702.
12. WHO. NATIONAL BURDEN OF DISEASE STUDIES: A PRACTICAL GUIDE. Geneva 2001.
13. Wilkins R, Adams OB. Health expectancy in Canada, late 1970s: demographic, regional, and social dimensions. Am J Public Health. 1983 Sep;73(9):1073-80.
14. Arnesen T, Nord E. The value of DALY life: problems with ethics and validity of disability adjusted life years. BMJ. 1999 Nov 27;319(7222):1423-5.
15. Hyder AA, Rotllant G, Morrow RH. Measuring the burden of disease: healthy life-years. Am J Public Health. 1998 Feb;88(2):196-202.